



Late Life Planning Guide

Developed by the BC CEO Network with funding provided by the Ministry of Social Development & Poverty Reduction



community living society

The Importance of Planning

Early and ongoing planning is an important predictor of people's health, wellbeing, and quality of life. A pro-active approach to planning includes recording in advance the important details. This helps link decisions made now to visions of how people want to live when they are older.

DISCLAIMER

The information in this Guide, including, but not limited to text, graphics, images, and other materials are for informational purposes only. The material contained in this Guide is not intended to be a substitute for professional medical or legal advice. Always seek the advice a physician, qualified health practitioner or legal professional with any questions you might have about late life planning.



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Who Should Use This Guide

This Guide is developed for agencies providing service for people with an intellectual or developmental disability (IDD) as they age. It also may be needed if there is a sudden or unexpected event at any age.

The Guide highlights some of the key considerations when planning in the later stages of life. It is not intended to include components that are already part of the CLS annual and ongoing person-centred planning processes.

Planning with people as they age is part of an integrated whole life person-centred approach to service provision.

Values

When planning with Supported Individuals in late life, we need to consider the core principles that guide our thinking and interactions while staying attuned to these throughout the process.

Preparation is Key to Well-being as People Grow Older. Early and ongoing planning for late life is an important predictor of people's health, wellbeing, and quality of life. Successful aging is not measured simply by longevity, but more importantly by their opportunity to engage meaningfully in the areas of their life that are important to them. As people prepare for changes in their lives, we can help to promote practices, adapt our supports, and explore alternative activities that maintain quality of life. **Person Centred Thinking** includes continuously listening, learning, and understanding what is *important to* and what is *important for* the Supported Individual, working together to ensure a balance between these perspectives. (Adapted from Helen Sanderson et al, 2008).

Quality of life can change dramatically through the aging process. Using a person-centred thinking approach will ensure everyone is attuned to these changes.

Whole Life Planning and Quality of Life is a wholistic approach that goes beyond focusing only on the health and safety issues, but as well to the matters that are important to people to experience a good quality of life. The Quality of Life Domains (Schalock & Verdugo, 2002), guide this focus:

- **Emotional Wellbeing:** Supported Individuals feel safe in their home and community. They have a positive sense of self and trust the people in their lives.
- **Interpersonal Relations:** Supported Individuals have meaningful relationships with family and friends.
- **Material Wellbeing:** Supported Individuals have the financial resources to do the things that are important to them.
- **Personal Development:** Supported Individuals pursue their interests, have opportunities for personal growth and skill development, and have access to necessary information and support.
- **Physical Wellbeing:** Supported Individuals are physically healthy and active. They have access to the health care they require.
- **Self-Determination:** Supported Individuals make decisions in their lives about things that matter to them.
- **Social Inclusion:** Supported Individuals participate in community life in roles they and society value.
- **Rights:** Supported Individuals have autonomy, and their decisions are respected.



“We have learned that there can be healthy development in risk taking... and there can be crippling indignity in safety!”

(1972)

Self-Determination and The Opportunity for Choice and Voice naturally flow from person-centred thinking. Putting people and their choices first to live as fully as possible, for whatever time they may have.

Embedded in this principle is the concept of the dignity of risk. People should have the freedom to make informed choices that may expose themselves to a level of risk in order to have the quality of life they want.

Dignity and Respect goes beyond simply honouring people's choices. It also refers to the ways in which we explore concerns and extend services to Supported Individuals. They, like all citizens, have the right to **Equal Treatment**.

Understanding that biases within health care and other systems exist, based on age or disability, and this can limit assessments and access to treatments. Too often, symptoms are dismissed, and no diagnosis provided.

Dignity & respect require **Informed Choice**. Providing opportunities to explore end-of-life planning, to talk about and share their wishes, and understanding what CLS can reasonably agree to offer, and what will need to be addressed by others.

For example, a Supported Individual may wish to die in their home. However, in expressing this wish, they need to understand that the CLS may have prohibitions on some aspects of their care that may be needed. (e.g., administering narcotics) Planning must include if and how this can be managed, what other choices might be possible for them or what will need to be in place for CLS if this is outside our scope of care.

Honouring the pivotal role that **the Personal Support Network** plays for Supported Individuals, particularly in the late stages of their lives, is fundamental to supporting their quality of life as they age. Research confirms the importance of nurturing existing relationships and broadening their networks can play in people's lives. This helps to ensure that they have a strong circle of people who matter to them to provide support and advocacy as they age, including those people they may define as family as a result of important social interactions.

The focus on personal support networks includes involving those long-term employees (former or current), who may be important to the person. They may play a major role in the life of them, especially for those who may not have an engaged family and/or an extensive circle of support.

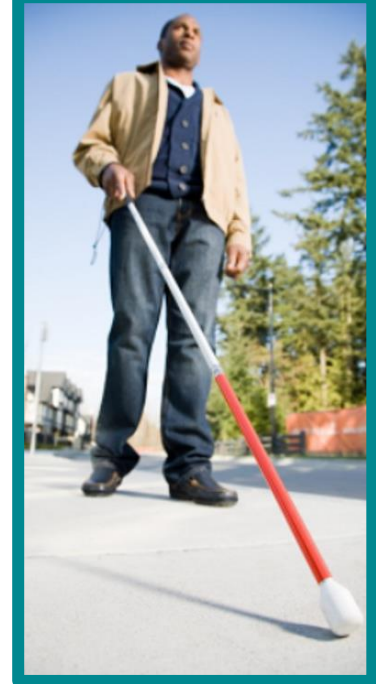
Part of engagement with the families and other members of a person's personal support network must involve exploring each person's comfort and preferred roles in supporting their loved one as they age. Discussions about end-of-life preparation are key but may prove challenging especially if they are left until the end is near. Tensions may surface and make conversations difficult. These are common realities for many families. Debates about the Supported Individual's assets, finances, palliative care choices, etc. can arise when the loss of a loved one is imminent. When possible, these potential conflicts/pressures should be explored before the need arises, with clarity around roles. This is especially important when a person's care has been entrusted to an organization and there are strong ties with employees and roommates of the household.

Successful Aging

A Planning Overview

It is a privilege to support people in their later stages of life. This is the result of the collective advocacy of the personal support network and Supported Individuals. The average life expectancy has increased for both the general population and those with disabilities. People are thinking about retirement, changes in their health and mobility, and other common dimensions of aging. It is essential when planning with people that we consider quality of life, their beliefs, values and wishes to guide thinking and interactions throughout the process.

Early and ongoing planning for later life is widely considered an important predictor of people's health, wellbeing, and quality of life as they age. Successful aging is not measured simply by longevity, but more importantly by the person's opportunity to engage meaningfully in the areas of their life that are important to them. Keeping these front and center as people prepare for changes in their lives, promotes exploration of alternative activities that can maintain quality of life as people age.



When to Plan

While it is never too early to start planning, it can be too late, therefore Late Life Planning will start at 50 years of age, or 40 for those who have a diagnosis of Down Syndrome. Information in the plans should be confirmed and updated annually. For those with intellectual or developmental disabilities it can be used when it is suspected they are experiencing a cognitive change or earlier to establish a baseline.

In addition, Late Life Planning will commence in the event of a sudden or unexpected health event, regardless of age.

Each section discusses key considerations for socio-emotional, health, legal & financial matters. The Guide should be used as a tool to supplement the annual a planning processes, not a separate activity.

No Personal Support Network

Some people may not have any family or personal support network members to support them in their planning. In this case CLS will plan with this Supported Individual.



Socio-Emotional

Whole life planning is a person-centred approach to assist people to think about and plan for their future. Social emotional health includes strong relationships with their personal support network and being active and engaged in life. Exploring the lifestyle people want as they age, where they want to live, who they want to socialize with and, what they want to accomplish is all part of the process.



Health Care

Supportive and compassionate care integrates a person's wishes for their health care, specific interventions, spiritual and cultural beliefs, and advocacy.



Legal

Discussing and sharing legal documents with the people they trust, with those who need to be informed and choosing who would make decisions on their behalf if they cannot is important.



Financial

Financial planning can help maintain a good quality of life as people age.

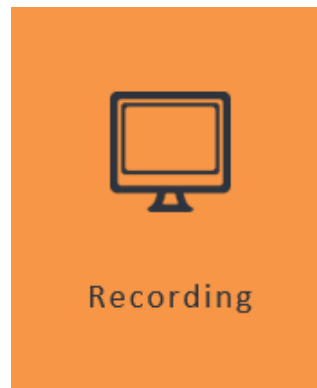
Who Needs to Be Informed

Part of the planning process includes:

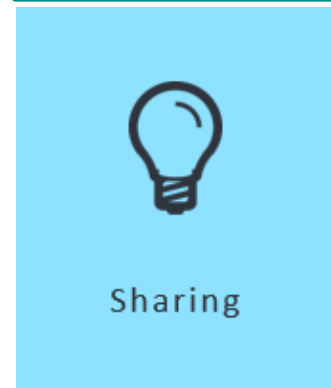
- Ensuring a person's wishes are mutually understood by all.
- Formalizing and sharing documents, with the Supported Individual's consent, with their personal support network and appropriate professionals.
- Ensuring personal support network members understand a person's wishes and be able to help advocate for what is needed.



Identify any existing plans that the person and/or personal support network may have put into place related to the person's future. These can include Advance Care Plan, Wills and Estate planning, end of life care plans, etc.



Important documentation needs to comply with the provincial laws. Some documents will need to be legally confirmed, and others witnessed. Typically, they must be in writing (physical copy) and not online.



Identifying who and what parts of the plan needs to be shared with health professionals, emergency professionals, financial institutions, employers, personal support network members, decisions makers, etc.

***“Life is what you celebrate. All of it.
Even its end”***



LATE LIFE PLANNING

Successful aging is not measured simply by longevity, but more importantly by the person’s opportunities to engage meaningfully in life based on their own choices.

Late Life Planning at CLS

Late Life Planning is the term used when we plan for typical life stages in a person's advancing years. At CLS, this process is implemented for those who are supported in Staffed Homes, Home Share and Supported Living, and are 50 years of age or older, or 40 if they have a diagnosis of Down Syndrome.

This planning process includes discussions about aging, and the accompanying changes that can occur. The focus is about promoting discussions about what matters to the Supported Individual to protect their preferences and quality of life.

Late life planning can encompass all aspects of what defines a person's quality of life such as:

- Health and health care
- Legal matters
- Financial matters
- Work/community life
- Mental well-being
- Social and personal support (resources)



Socio-Emotional



Questions about the future

Self-Determination is the opportunity to engage in life in a way that is meaningful for the person. Putting people and their choices first supports them to live as fully as possible based on their beliefs, values and wishes.

Part of engagement with the families and other members of a person's personal network must involve exploring each person's comfort and preferred roles in supporting their loved one as they age. Discussions about end-of-life preparation are key but may prove challenging especially if they are left until the end is near.

Tensions may surface and make conversations difficult. These are common realities for many families. Debates about the individual's assets, finances, palliative care choices, etc. can arise when the loss of a loved one is imminent. Where possible, potential conflicts/pressures should form part of late life planning exploring before the need arises. Clarity around roles must be defined. This is especially important when a person's care has been entrusted to an organization and there are strong ties with employees and roommates of the household.

Late Life Planning involves discussions about aging, and the accompanying changes that can happen. This can occur during CLS's existing person-centred planning processes while always considering a whole life perspective.

Home and Home Life
<ul style="list-style-type: none">• What about your home life – the people, your personal space, the activities you engage in at home?• What are the most important things to have as part of your home life as you age?• What are the things that may need to change about your home as you age?• Is your home accessible? Can it be made accessible? (e.g., Stairs, Bathrooms, Doorways)• If you were not able to live where you are now as you get older, what kind of living situation would be important to have?
Community Life
<ul style="list-style-type: none">• What are the things you like to do in your community?• Where are the places you like to spend time in community and how do you get to these places?• What are important about the places where you spend time? (Think about the domains of personal development - social, emotional, physical, spiritual, intellectual)• How might your involvement and/or access to these places or activities change as you get older?• What can we do to help you continue doing the things you like in your community as you age?
Work and Volunteer Activities
<ul style="list-style-type: none">• What does retirement mean to you? What do you expect to be doing when you retire? How will you help to make that happen?• What kinds of paid work or volunteer activities are you doing right now?• Do you want to continue to do these jobs or volunteer activities as you age?• Are there parts of your jobs or volunteer activities that have heavy physical demands or repetitive physical activity (e.g., lifting, walking, standing, bending, stooping, reaching, etc.)? Are there exercises or other activities that you can do to help you meet these demands? What if you are no longer able to manage these demands?• What, if any job accommodations do you need for your current job... will these last over time as you age?
Psychological Wellbeing
<ul style="list-style-type: none">• What are the things that help you feel good about yourself?• What are the things that make you unhappy or give stress?• As you age things will change – What will help you to manage these changes?• How do we talk about grief and loss? (e.g., of a loved one, major health changes)
Relationships and Connections
<ul style="list-style-type: none">• Who are the people that are important to you?• As you age will it be more difficult to connect with these people?• What can we do to help you maintain these relationships as you age?

Making the Most of Exploratory Questions

The above exploratory questions are not intended to be prescriptive. They are meant to prompt ideas about how to get discussions started to effectively engage each person, and their families/personal support networks and to start taking steps to think about and prepare for later life.

Open Ended Questions Lead to Better Discussions/Exploration: As much as possible, it is best to use open ended questions that allow people to reflect on things they have been thinking about, or wondered about, rather than answering yes/no to a list of questions like: Do you have a will?

Have Examples Ready: Make sure to have ideas ready when leading with a general question like “*What do you like best about where you are living right now*”. Often a simple example or two can help people feel more confident answering these questions. Personalize these examples if you can but pose as a question to be sure you are on track rather than as an assertion i.e. *When I see you at home, I notice how much you seem to like helping with the cleaning... you always seem to be busy with cleaning your room or the kitchen and seem proud of your work... is this something you like about your home life?*

Be curious: Take time to understand and dig deeper when people are talking or showing you things. This practice helps both you and the speaker to gain more clarity i.e., *What do you mean when you say, how would that look if you had that?*

Add prompting questions to the forms you use: Rather than leaving these discussions to chance, make sure you document the questions so you can remember to touch on each topic area. Do this as a team so that everyone is using the same approach at intake or during planning. Explaining why you have the forms and what you are recording will help ease the anxiety that this can create.

Practice answering these questions yourself: Firsthand experience in thinking about these topics is important. Not only does it give you more credibility to the people you are inviting to explore these topics, it also can help you feel more confident and comfortable asking these types of questions.

Be sensitive to the reaction(s) of the individual: These questions and ideas may be very new to the person, and they could have an emotional impact as people think about what matters to them. They may also need to gain confidence to talk honestly and openly about their wishes and preferences, especially if they have not had a lot of experience giving voice to their thoughts. Follow their lead and move at their pace.

This is a process, not a task. Supporting people to consider their wishes, needs, and preferences is about helping them to trust that they will be heard and respected, and to gain confidence that our interest in their ideas is authentic. Resist the urge to treat these questions as a checklist to complete. Rather, engage in the deep and active listening required and recognize that you will be engaging in these conversations on an ongoing basis – one conversation builds on the next.

Dignity and respect go beyond simply honouring people’s choices.

It also refers to the way in which we explore concerns and extend services to individuals who live with intellectual disabilities.



Health Care

Dementia and People with Intellectual Disabilities

According to the Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities: “people with IDD who are aging face many of the same age-related health issues that people without disabilities face. However, they may develop health issues such as dementia at an earlier age and their initial symptom presentation may differ from that of the general population. In particular, adults with down syndrome are likely to experience dementia at a much younger age and with greater frequency than would be expected.”

The NTG-Early Detection Screen for Dementia is a tool that can be used for the early detection/screening of adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. (See “Forms” for the tool)

CLS will be using this tool on an annual basis for all Supported Individuals at 50 years of age, or 40 for those who have a diagnosis of Down Syndrome. For those with intellectual or developmental disabilities it can be used when it is suspected they are experiencing a cognitive change or earlier to establish a baseline. (See ‘Forms’ for the NTG- Early Detection Screening Tool).

Advance Care Planning

As people age, they start planning for later life. Late life plans include health and personal care, estate, and financial planning. An Advance Care Plan is one part of this planning. An Advance Care Plan is a written summary of an adult's wishes or instructions to guide health care professionals and a substitute decision maker if that person is asked by a physician or other health care provider to make a health care treatment decision on behalf of the adult.

As with all planning, advance care planning is deeply personal and must be guided by the values and priorities of the person and their family/legal decision maker. Planning includes supporting people to think about their beliefs, values and wishes, sharing them with the people they trust and identifying who would make decisions if they can not.

Plans will be accessible on Sharevision in the Supported Individuals’ file in a report titled *Late Life Planning Report*. Copies should be shared with family/friends, health care providers, physicians and alternative decision makers.

An Advance Care Plan can be changed or cancelled at anytime by the Supported Individual and legal decision-making authority. Inform health care providers about the change(s) and provide updated copies.

Read and Thompson-Hill (2008) report that individuals with IDD receive fewer screening tests and investigations and are 4 times more likely to die of treatable illness than those in the general population.

An Advanced Care Plan documents a person's wishes and can include:

1) **An Advance Care Summary (See "Forms" for an example)** An Advance Care Summary can be used as a guide/overview when developing an Advance Care Plan. The summary outlines the important components, with some items / forms being optional. The summary can be included at the beginning of the Advance Care Plan to clearly outline what has been included and when it was last updated. It is important to ensure the appropriate legal advisors, health professionals, decision makers and important people are enlisted in completing an Advance Care Plan. Forms will need to be formalized with the appropriate professionals. Work with the person's health care professional to determine who needs to assist with which forms.

2) **Medical Orders for Scope of Treatment (MOST) (See "Forms" for an example)** The medical order for scope of treatment or MOST form helps care providers honour what is important to the person. Medical Orders for Scope of Treatment (MOST) are official documents (Medical Orders). Physicians and other health care professionals use the MOST to relay the treatment wishes and decisions regarding a person's care to others who may be part of the integrated care team.

It is a doctor's or nurse practitioner's order based on [advance care planning conversations](#) that explore the person's values, goals, and the range of beneficial treatments. Once decisions are made the doctor will record this on the medical order for scope of treatment or MOST form.

The medical order for scope of treatment form provides orders for:

- [Cardiopulmonary resuscitation \(CPR\)](#) should the person's heart and breathing stop. CPR is when we try to restart a person's heart and breathing with machines and chest compressions.
- Medical treatments can focus on comfort goals or be very aggressive and include intensive care.

Many people lose the ability to decide about their own health care when they become very ill. If the person cannot communicate their wishes or make health care decisions, the MOST order can direct care.

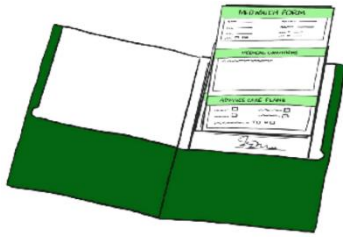
A Supported Individual is always asked to give consent for health care treatment, as long as they are able. A MOST can be changed at any time and should be reviewed on an annual basis with the physician/nurse practitioner or if there has been a change in health care needs, a person is hospitalized or if the person moves. A MOST should be brought with people to the hospital, emergency room, medical appointments, and supported living.

A MOST will include:

- Cardiopulmonary Resuscitation
- Medical Treatments
- Comfort Goals

It is suggested that a MOST be developed for anyone who:

- Lives with a chronic illness
- Changing residences
- Health professionals caring for a person in their home
- Wants to document plans about future medical care and treatment



What is a “Greensleeve”?

When is it Used?

Greensleeve is a green plastic page protector that is placed at the front of the health record to identify resuscitation status, scope of treatment and store advance care records. Greensleeves are like a health care passport, and it legal decision makers and any advance care planning documents. They are used in end-of-life planning to ensure important documents are readily accessible. It's a good idea to take it to all medical appointments and clinic or hospital visits and keep it on the fridge in the person's home. This is where emergency personnel will look for it if needed.

A Green Sleeve can typically be picked up at Hospice or at any medical clinic. It will come enclosed with all or some of the following components:

- [Emergency Information](#)
- Documents or information regarding legal designate for decision making (i.e. Representation Agreement, Committee, [Temporary Substitute Decision Maker](#))
- Medical Order Scope of Treatment Form (MOST)
- Enclose other written Advanced Care Planning documents and Advanced Directives

Legal

Confirming Legal Decision-Making Authority

An adult (over the age of 19 years) is presumed capable. As a person ages, it is important to confirm the person and/or people that are able to make decisions on behalf of the individual if they are unable to do so on their own behalf. Some people may have their own legal decision-making authority unless, they have a legal Guardian (Private Committee, Public Guardian and/or Trustee) or designated legal decision maker (i.e., Representative, Power of Attorney, Temporary Substitute Decision Maker). It is important to have copies of any documents, understand the roles and responsibilities, and provide documents to appropriate organizations when needed.

Private Committee: A 'Private Committee' (pronounced caw-mi-tay, or caw-mi-tee, with emphasis on the end of the word) is a person or body usually appointed by the BC Supreme Court under the Patients Property Act to manage the financial, business, legal affairs (Committee of Estate) and/or personal and health care decisions (Committee of Person) of someone who is not capable of looking after these matters. Most often Private Committees (Estate / Person) are family members or friends.

Power of Attorney: A Power of Attorney is a document that appoints another person, called an "attorney," to make financial and legal decisions if the person is no longer able to do so. Under this authority the "attorney" cannot make health care decisions on behalf of the person. (An "Attorney" is not the same as a lawyer or a barrister and solicitor.)



Representative: A ‘Representative’ is a person named by an adult in a *Representation Agreement* to support the adult to make decisions or make decisions on their behalf.

There are two types of representative agreements.

- [Representation Agreement \(Section 7\)](#) - An adult may name a representative to help make decisions, or make decisions on behalf of the adult, with respect to personal care and health care, the routine management of financial affairs and obtaining legal services for the adult and instructing counsel.
- [Representation Agreement \(Section 9\)](#) - An adult may name a representative to do anything that the representative considers necessary in relation to the personal care or health care of the adult.

Temporary Substitute Decision Maker (TSDM): A ‘*Temporary Substitute Decision Maker*’, is chosen by a health care provider [Under the Health Care (Consent) and Care Facility (Admission) Act (HCCCFAA)] to make health care decisions on behalf of a person who is unable to do so.

HCCCFAA S.16 Outlines:

1. To obtain substitute consent to provide major or minor health care to an adult, a health care provider must choose the first, in listed order, of the following who is available and qualifies under subsection (2):
 - a. the adult’s spouse;
 - b. the adult’s child;
 - c. the adult’s parent;
 - d. the adult’s brother, sister, grandparent or grandchild;
 - e. anyone else related by birth or adoption to the adult;
 - f. a close friend of the adult;
 - g. a person immediately related to the adult by marriage.
2. To qualify to give, refuse or revoke substitute consent to health care for an adult, a person must:
 - a. be at least 19 years of age;
 - b. have been in contact with the adult during the preceding 12 months;
 - c. have no dispute with the adult;
 - d. be capable of giving, refusing or revoking substitute consent, and;
 - e. be willing to comply with the duties in section 19.
3. If no one listed in subsection (1) is available or qualifies under subsection (2) or if there is a dispute about who is to be chosen, the health care provider must choose a person, including a person employed in the office of the Public Guardian and Trustee, authorized by the Public Guardian and Trustee.

Note: A health care provider is not required to do more than make the effort that is reasonable in the circumstances to comply with this section.

Advance Directive – An Advance Directive is a legal option for those who have the capacity to make plans in advance about their future health care. This plan will be followed directly if the person becomes incapable of making decisions themselves. There is no requirement (or need) to have a decision maker in place. The person shares their decisions for health care treatments directly with the health care provider. No one will be asked to make a decision on behalf of the person when an Advance Directive is in place.



Financial

Estate Planning is the process of arranging the management of how a person's estate will be handled after they have died. Everyone over the age of 18 years should have a Will. In the absence of a Will any assets will distributed according to the provincial laws and the courts. The [People's Law School](#) is a non-profit society in BC, providing free education and information. (e.g., Financial & Legal Matters, Health & Personal Care, Making Decisions for Someone Else).

A Last Will and Testament – Refers to the most current version of a person's Will. It details what will happen to any assets/property after they have passed.

A Will includes an Executor (who will carry out the person's instructions), identifies any assets, real property and the end-of-life recognition instructions. When a person has a valid Will, it is the responsibility of the Executor named in the Will to handle the funeral arrangements and administer the estate. *It is recommended that the Executor complete the following duties:*

- Completing an inventory and valuation of all assets and debts;
- Gathering names and addresses of all beneficiaries and next-of-kin;
- Cancelling subscriptions and charge cards, redirecting mail and wrapping up other personal matters;
- Taking control of all assets, including the transfer of ownership registrations and the collection of any debts;
- Paying all valid or proven debts left to the estate;
- Filing tax returns for the deceased and for the estate;
- Selling assets as necessary and distributing the estate; and
- Preparing and obtaining approval from the beneficiaries, heirs-at-law or the court for accounts showing assets, receipts, disbursements, and distribution of the estate.

Beneficiary Designations – Beneficiary designations are part of a person's Will. This identifies who will receive their assets after they die. If the person makes a designation, then those assets will be passed to the those identified as a designated beneficiary.

No Will / Next of Kin – If there is no Will and no next of kin able to handle the responsibility, the [Public Guardian & Trustee](#) (PGT) may consider administering the estate. The PGT does not administer estates if the estimated gross value of the estate's assets are insufficient to pay for funeral costs and PGT fees.

If there is no Will, there is no executor and no directions on how an estate should be divided. Certain individuals are eligible to apply to the BC Supreme Court for a **Grant of Administration**. If the application is successful, this person will be able to manage and distribute the estate.

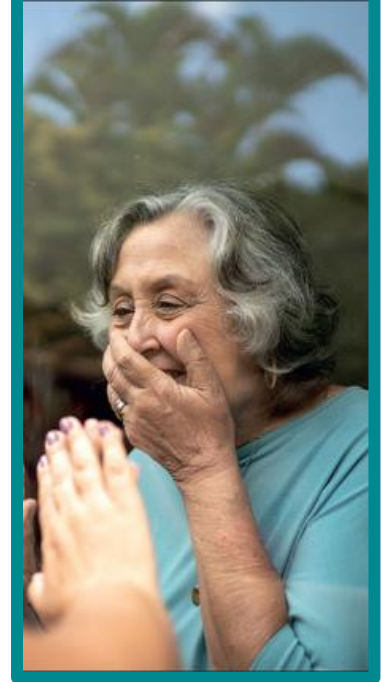
If no one qualifies to receive the estate under the rules, the estate goes to the provincial government.

Late Life Planning Checklists

Socio-Emotional Checklist

As people age it is important to support them to select and organize the services and supports that they may need to live in and be engaged in community.

- Home & Home Life
- Community Life
- Work & Volunteer Activities
- Psychological
- Well-Being
- Relationships & Connections
 - If they have pets: What plans would they like to have in place?
 - End of Life Recognition (Refer to End of Life Planning Section)



Health Care Checklist

To be maintained on a regular basis not only for Late Life Planning.

Understanding a person's health care needs is important as people age. They may no longer recall their history, and in the event that they are no longer able to communicate for themselves a detailed record will fill in any gaps in knowledge. [MyVoice](#) is an Advance Care Planning Guide published by the Ministry of Health to help people express their wishes for future health care treatment.

- Advance Care Plan
- Advance Care Plan - Summary
- MOST
- Legal Decision Maker(s)
- BC Personal Health Number
- Doctors (Primary / Other) (Name, Contact Information)
- Dentist (Name, Contact Information)
- Health Care Professionals (Name, Contact Information)
- Personal Health History
 - Conditions, how they are controlled, treated. Past information: surgeries, accidents & hospitalizations.
 - Doctor visit summaries (as relevant)
 - Discharge summaries
 - Test results
 - Baseline of abilities
- Pharmacist (Name, Contact Information)
 - List of medications
 - Supplements
 - Over-the-counter medications
- Immunizations
- Family Health History
- Assistive Devices (Name, Contact Information)

Legal and Financial Checklist

Estate planning requires detailed, formalized documentation to ensure a person's directives will be carried out in accordance with their wishes. A trusted person should be identified. They will be able to assist with financial and health decisions when the person no longer has the capacity to do so themselves.

Contact Information

- Lawyer, Trustee, Public Guardian
- Bank (Locations, Credit Cards)
- Trust Fund, Registered Disability Savings Plan

Last Will and Testament

- Guardian for minor children
- Guardian for pets
- List of all personal property and assets
- Executor

Beneficiary Designations

- Savings accounts, investment accounts
- Life insurance policies
- Pensions, Trust Funds, CPP/OAS
- Registered Disability Savings plans, RRSP's, Tax Free Savings Accounts

Insurance Policies

- Life insurance
- Home insurance
- Car insurance

Proof of Identity Documents

- Social Insurance Number, Identity Card, Passport
- Birth, marriage and divorce
- Prenuptial agreements

Digital logins and Passwords

- Bank & financial accounts
- Social media & email accounts & cloud storage
- Logins for streaming services, utilities
- Digital files, photos, documents (hard drives / thumb drives)

Titles and Property Deeds

- Titles/deeds for homes, vehicles, real estate
- Home – Is there a rental agreement, damage deposit?
- After the person passes, will the room/home be locked until Trustee attends?

Sudden / Unexpected Events

Sudden or unexpected health events such as a serious illness or injury can change a person's life in many ways. With physical changes that can result from a serious health event, it is also common to experience emotional and psychological reactions. Initial resistance and confusion about treatment options are normal responses. Over time people will typically come to terms with the situation, accept change and adapt to a different routine.

Supporting people through the change and ensuring the appropriate plans are in place, documentation is readily accessible and organized takes immediate priority. It is important to encourage conversations with family and health professionals about the support and treatment options available and next steps.

Detailed Documentation

It is essential that all relevant documentation be easily accessible and organized. It is recommended to ensure documentation updates are part of the regular planning cycle. Having documents ready in the event of a sudden change or unexpected event will reduce the anxiety that often goes with these situations. Refer to the relevant checklists for more information on some of the common documents to organize.



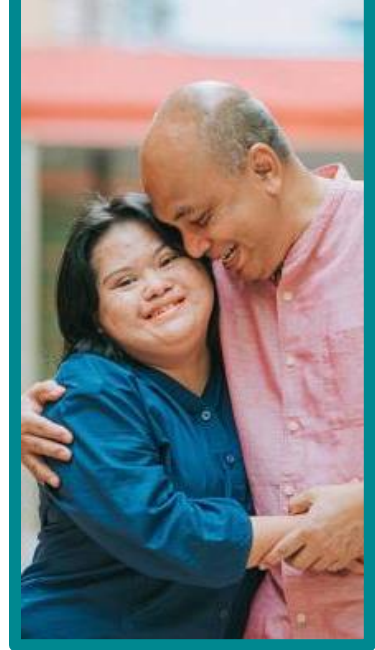


END OF LIFE PLANNING

What is End of Life Planning

End of life planning prepares a person to get their affairs in order and determines how and where they want to spend their remaining days. The goal is to provide people with the tools needed to make financial and health care decisions and to carry them out in the event that they no longer have the capacity do so themselves.

End of life care ensures the plans made in late life planning are carried out. This includes comfort, treatment decisions, quality of life, support for the person's family and the psychological, cultural and spiritual needs for the people dying and their families. During end of life care the support team should be aware of any cultural/spiritual beliefs may have and if there are any traditions that need to be included. For example, is embalming permitted? Are there any other cultural requirements that need to be observed?



The aging process is one we all as human beings must navigate if our lives are not cut short before we get the opportunity. In supporting people with intellectual disabilities, we are not to navigate it for them, but help hold the space for them to think about and engage the people that matter to them most, so they do not make this journey alone. In this way, we can learn from them and challenge ourselves to new perspectives and approaches as we discover the best ways to engage everyone involved to support them in their journey.



Socio-Emotional

End of life care involves an integrated team that includes CLS employees, health care professionals, personal support network and family members. It includes the support and medical care given during the time around death. For those people who do not have a family or a network of important people, CLS employees will play an important role in communicating and sometimes advocating for the Supported Individual.

Informed choice must be an integral part of the discussion surrounding end-of-life planning. For example, an individual may wish to die in their home. However, in expressing this wish, they need to understand that the organization may have prohibitions on some aspects of their care (e.g., administering narcotics) should they be needed. Therefore, planning must include if and how this can be managed, what other choices might work for the person, or resources the organization might need to take if this becomes an important feature of care.

Although it may feel uncomfortable or there are concerns about the perceived discomfort of the person, it is critical that we not avoid these conversations. These discussions are key features in any form of late life planning and can be instrumental in helping all involved to feel confident and comfortable supporting the person's wishes.

Finally, and perhaps most essentially, honouring the pivotal role that **personal support network engagement** plays for each person, particularly in the late stages of their lives, is fundamental to supporting their quality of life as they age. Research confirms the importance personal support network members can play in people's lives, recognizing that they not only provide critical informal and natural safeguards, but also help to reduce isolation and promote dignity. Late life planning should both continue to nurture existing relationships and to broaden these networks. This helps to ensure that they have a strong circle of people, who matter to them to provide support and advocacy, and who they know they can count on as they age, which may include long-term employees.

Part of engagement with the Supported Individual's personal support network must involve exploring each person's comfort with and preferred roles in supporting their loved one as they age. Discussions about end-of-life preparation are key but may prove challenging especially if they are left until the end is near.

Health Care

The planning process for end-of-life care and/or palliative care must be developed with all the relevant stakeholders. The plan must clearly delineate the care responsibilities, scope of care, and delegation of tasks for each person. It is important for employees to have appropriate support and training during this time. This includes understanding what is needed for employees to carry out their duties and the associated training that will be required for them to be successful and healthy.



Palliative Care is specialized medical care. It is used when people have a serious illness, regardless of the prognosis. Contact the home and community care office in your health authority or have a health care professional make a referral on the person's behalf. Palliative care can be provided in a variety of settings:

- At home.
- At the hospital.
- In a hospice.
- In a long-term care facility.
- In accommodations for residential services.

Planning for palliative care includes the personal support network and professionals. A plan should identify the care responsibilities, scope of care and delegation of tasks for each person. For those who wish to remain in their home, there is no cost for community nursing services or community rehabilitation services. There are fees for hospice care. Fees vary, depending on a person's situation.

To assist someone to receive end-of-life care / palliative care services the home and community care office in their location or their health authority can be contacted. A health care professional can also make a referral.

BC Palliative Care Benefits will support people who need end-of-life care and are at the end stage of a life-threatening illness and want to receive palliative care at home. This can be in the person's home, with family or friends, in a supportive/assistive living home, or in a hospice unit at a residential care facility.

The goal is to provide care at home and not be admitted to hospital. The same drug benefits and some medical supplies/equipment are available to those who choose to stay in their home.

Medical Assistance in Dying “...provides people, who are experiencing intolerable suffering due to a grievous and irremediable (incurable) medical condition, the option to end their life with the assistance of a doctor or nurse practitioner. Medical assistance in dying is provided only to legally eligible persons.” (Government of BC, March 2021) This service is only provided to people who can give consent. Consent through an alternate or substitute decision maker or through a personal advance directive is not eligible. Any person seeking medical assistance in dying should speak with their doctor, nurse practitioner or local health authority's care co-ordination service.

“People who request medical assistance in dying can be motivated by a range of factors unrelated to their medical condition or prognosis. These factors make some people vulnerable to request an assisted death when what they want and deserve is better treatment – to have their needs for care, respect, and palliative and other supports better met”

– Inclusion Canada

Death Doula - An End-of-Life Doula is someone who supports a person faced with an illness or terminal diagnosis. There are fees associated with hiring a Death Doula. *"The End-of-Life Doula can educate, advocate for, and empower clients by starting the conversation about death and embracing the dying process early.. Some of their tasks and skills may include:*

- *Advocate for the best possible experience for the client.*
- *Understand the physiology of death and the complexity of emotions that go along with the diagnosis of a terminal illness.*
- *Assist clients in creating and carrying out their health care treatment decisions.*
- *Are knowledgeable about legalities, options, and tools in Canada.*
- *Provide emotional, physical comfort measures and an objective viewpoint.*
- *Providing information needed to make informed care decisions.*
- *Facilitate communication between client, family and other care providers.*
- *Protect the client's dignity and the family's memory during the death experience.*
- *Allow the family to participate at their own comfort level."*

- End of Life Doula Association of Canada

Personal Assistance Guidelines

Delegation of Tasks

CLS employees are unregulated Care Providers (UCPs). Unregulated Care Providers (UCPs) provide care to people who require personal assistance with activities of daily living. UCPs are defined as paid care providers who are neither registered nor licensed by a regulatory body and who have no legally defined scope of practice (CRNBC, 2000). Their work setting includes the person's homes, group homes, community inclusion programs, etc.

The tasks performed by UCP's fall into two general areas:

1. **Assignable Tasks**
2. **Delegable Tasks** (or delegation of a professional task)

Assignable Tasks are tasks that are within the UCP's role description and training as defined by the CLS. These tasks are not considered to be specific to the Supported Individual and do not require ongoing professional judgement or monitoring.

CLS is responsible and accountable to develop role descriptions that clearly outline the tasks that can be assigned to a UCP in that agency/health authority. CLS will ensure the employee has completed an appropriate training program and supplement this training if needed, with on-the-job training.

The CLS Leader is responsible and accountable for providing ongoing supervision to assess the employee's ability to perform tasks within the role description.

Employees are accountable to their Leader for the satisfactory performance of these tasks.

Delegable Tasks are tasks that are client-specific and are outside the role description and basic training of the employee. Registered Nurses (RN), Registered Psychiatric Nurses (RPN), Physical Therapists (PT), or Occupational Therapists (OT) are responsible for delegating a professional task to CLS. Delegable tasks are normally performed by a RN, RPN, PT, OT, but under certain circumstances it may be in the best interest of the client to delegate the task to an employee

Although not able to delegate tasks to UCPs, Registered Dietitians (RD), Registered Respiratory Therapists (RRT), and Licensed Practical Nurses (LPNs) are able to provide consultation and training to UCPs for the delegable tasks. These professionals are usually health authority (HA) staff but may be contracted by the HA or employed by CLS.

Employees must receive training and demonstrate competence in the performance of the task. Employees cannot train another employee on the task. Each employee performing the task must be trained by the health care professional. The employees' Leader is responsible to ensure the employee has been trained in the specific task and for ongoing assessment of their ability to perform the task as taught.

The health care professional who delegates the task remains responsible for the determination of the Supported Individual's status, care planning, interventions and evaluation of care until they no longer require the task.

(Adapted from the Ministry of Health: Personal Assistance Guidelines 2008)

Scope of Care

Employees will provide assistance with the socio-emotional and personal care end of life needs for Supported Individuals. Employees understand the person's physical, emotional, mental abilities and challenges best and therefore can adapt assistance to the changing needs, maintaining quality of life and as much independence as possible.

For employees, end of life care involves providing:

- Physical comfort.
- Supporting an individual's social and emotional needs.
- Supporting spiritual / Cultural needs.
- Support for end-of-life tasks that need to be completed.

Employees should observe and document any physical and/or emotional changes and report changes to health professionals including:

- Changes in emotional state, confusion, fearfulness, lack of socialization, apathy.
- Changes in mobility, swallowing, elimination.
- Changes in appetite, loss of weight.
- Physical changes: bruises, bumps, skin anomalies, hair loss.

Regulated care is provided by health professionals (or in **some** circumstance delegated to unregulated care providers under strict guidelines) and can include:

- Pain and symptom assessment and management.
- Catheter care, colostomy care, skin & wound care.
- Collection of specimens (urine, stool, etc).
- Recording input/output.
- Monitoring of oxygen equipment.
- Use of specialized supplies and equipment.

Where a person has chosen to die at home, it is important that this wish is honoured, whenever possible. After exploring all the options available, there may be circumstances when this is no longer possible. Reconsideration may occur if the care has increased in complexity beyond the capacity of employees, the severity of the symptoms has increased and are no longer being managed effectively, comfort care is no longer effective, the person has changed their mind or the person's housemates are very distressed and can not be consoled.

Upholding the principles of dignity and respect also means talking about and opening the opportunity for people to fully participate in their exploration of end-of-life planning, defining their wishes, and discussing what the organization can reasonably agree to offer and what is out of scope and will need to be addressed by others.

Accommodating the Needs of the Household

Living with someone as they are nearing the end of their life can cause stress and anxiety for those who live with the person. Understanding the needs and the capacities of the entire household is part of the end-of-life planning process. During the remaining days some housemates may want to provide support and spend time with their housemate, others might find this too difficult. There will likely be an increase of visitors to the house (family, health professionals, etc.). How this affects those residing in the home needs to be taken into consideration.

When preparing an end-of-life plan, it is essential to include the other members in the household in the process. Monitoring the grief responses of the other housemates provides opportunities to provide grief and loss support in a way that will be beneficial for them to:

- Acknowledge the loss.
- Receive information and education about what to expect.
- Adjust routines, provide more opportunities for support from personal networks.
- Provide resources, access grief counselling.

Support and Employee Training

Example – “Jude”

Jude was 46-year-old woman. Jude had a busy life and enjoyed many activities in her community. Jude had an intellectual disability and lived in a 24-hour staffed home with 3 other people with intellectual disabilities. Jude's sister Mandy acted as her 'person responsible' as both Jude's parents were deceased. One morning Jude looked pale and hadn't eaten her breakfast. Jude indicated her stomach hurt and went back to bed. Subsequently Jude vomited and an appointment was made with her doctor for later that day.

The doctor referred Jude for x-rays and blood tests. They revealed ulceration in the intestine and Jude was referred to a hospital for surgery. The surgery revealed that Jude had advanced cancer and that treatment could only be palliative. A referral was made to the local palliative care service and Jude was discharged back to her home once she recovered from the surgery and post-acute care plan was arranged.

The palliative care service visited Jude at her home and assisted the staff to develop a support plan. The aim of the plan was to keep Jude comfortable and included medication for pain. While the plan included planned doses of an opiate for pain relief, it also included procedures to administer doses for severe breakout pain. Jude also received medication to manage her other symptoms, nausea and continence. The palliative care service arranged for a nurse to attend to administer the pain relief and, in line with policies, the residence had a procedure for authorising any PRN doses.

The palliative care service provided information to staff on Jude's prognosis, what could be expected over the coming months, and important signs to look out for. The palliative care service was available to answer staff questions, provided information on monitoring and side effects, and was available for consultation.

Staff were able to access palliative care supports and several staff attended additional short courses on bereavement. A focus of the training was to explore ways to support Jude and the other residents and how to talk about dying. The home used a copy of the Medical Order of Scope/ Goals of Care to assist them with understanding Jude's wishes and how best to communicate them to others.

The palliative care service made regular appointments with the Supervisor and sister to review Jude's care. Jude's sister and staff, with Jude, undertook to review her care plan to look at what activities and relationships Jude saw as important. The manager continued discussion with the house supervisor to monitor staff wellbeing.

Jude remained in her home for a further three months and participated in day activities when able. There were several inpatient admissions to hospital to review Jude's pain management and stabilise symptoms. Pain and other symptoms increased in severity and Jude became less able to eat and keep food down. Despite every effort, Jude was not able to be made comfortable in her home and the palliative care service arranged for her to be admitted to a hospice. Her roommates were able to visit Jude and several days later Jude died peacefully in the presence of her family and friends.

Access to debriefing was arranged as required as well as assistance with planning for bereavement. Jude's sister and the staff at the home made arrangements for a celebration of life. Staff created several opportunities for Jude's roommates to remember her.

-Adapted from Disability Residential Services Palliative Care Guide

End of Life Support

The end-of-life stage can be demanding for employees, housemates, family and friends. Access to support during this time is essential. Support can include:

- Information about the options available for care.
- Information about the prognosis / disease specific information.
- Community health supports.
- Palliative care services.
- Grief support groups.
- Support by community, personal networks, family & friends.
- Cultural / Spiritual support.

End of Life – What to Expect

As a person is nearing the end of their life, their body will go through a number of physical changes, much of which is normal and to be expected. Each person is different and may exhibit symptoms in a different way, have some of the symptoms, and none at all.

A dying person may...

- Sleep for longer periods of time.
- Have difficulty walking.
- Increased activity and communication followed by hours/days of sleep unresponsiveness.
- Become confused and/or restless, unable to recognize familiar people, their surroundings.
- Experience emotional and spiritual changes, depression, anxiety.
- Eat and drink much less.
- Have difficulty swallowing.
- Have irregular or shallow breathing.
- Develop wet-sounding breathing or moaning.
- Become unresponsive.
- Lose control of bladder / bowels.
- Have a change in body temperature.



Things you can do...

- Plan for visits when the person is awake and alert.
- Try to minimize noises or sounds that may be unpleasant to the person.
- Serve smaller portions of food / drink.
- Apply moisturizer to the person's lips to combat dryness.
- Tell the person what you are doing before you do it.
- Drops to prevent eye dryness.
- Speak slowly, calmly.
- Gentle music, forest/ ocean sounds.
- Foot / hand massages.
- Providing pleasant scents that appeal to the person (e.g. favorite scents).
- Help with positioning changes on a regular basis to prevent bedsores (pressure ulcers).

Saying Goodbye...

For many people, it is important to say good-bye to the person. The person at the end of their life may want to say goodbye to those in their life in-person or through letters, telephone conversations or video. Supporting the person to say goodbye is an important part of the process of letting go.

“I was confused – I didn’t know what would happen next”
“Everybody else talked around me but no-one talked to me”

Quotes from people with Intellectual and/or cognitive disability about their experience of access to palliative care services; Holliday, A. (2016)

End of Life Planning Checklists

Questions for Exploration

- Does the person want to remain at home for their remaining days or go to hospice?
- Does the home have the capacity to care for the person at the end of their life if they wish to remain at home?
- Does the person want to receive any visitors during their remaining days? If so, who should be included on the list?
- Are there any cultural or spiritual practices that should be included?
- Have housemates been included in the discussions about what to expect, what support they need?



End of Life Checklist

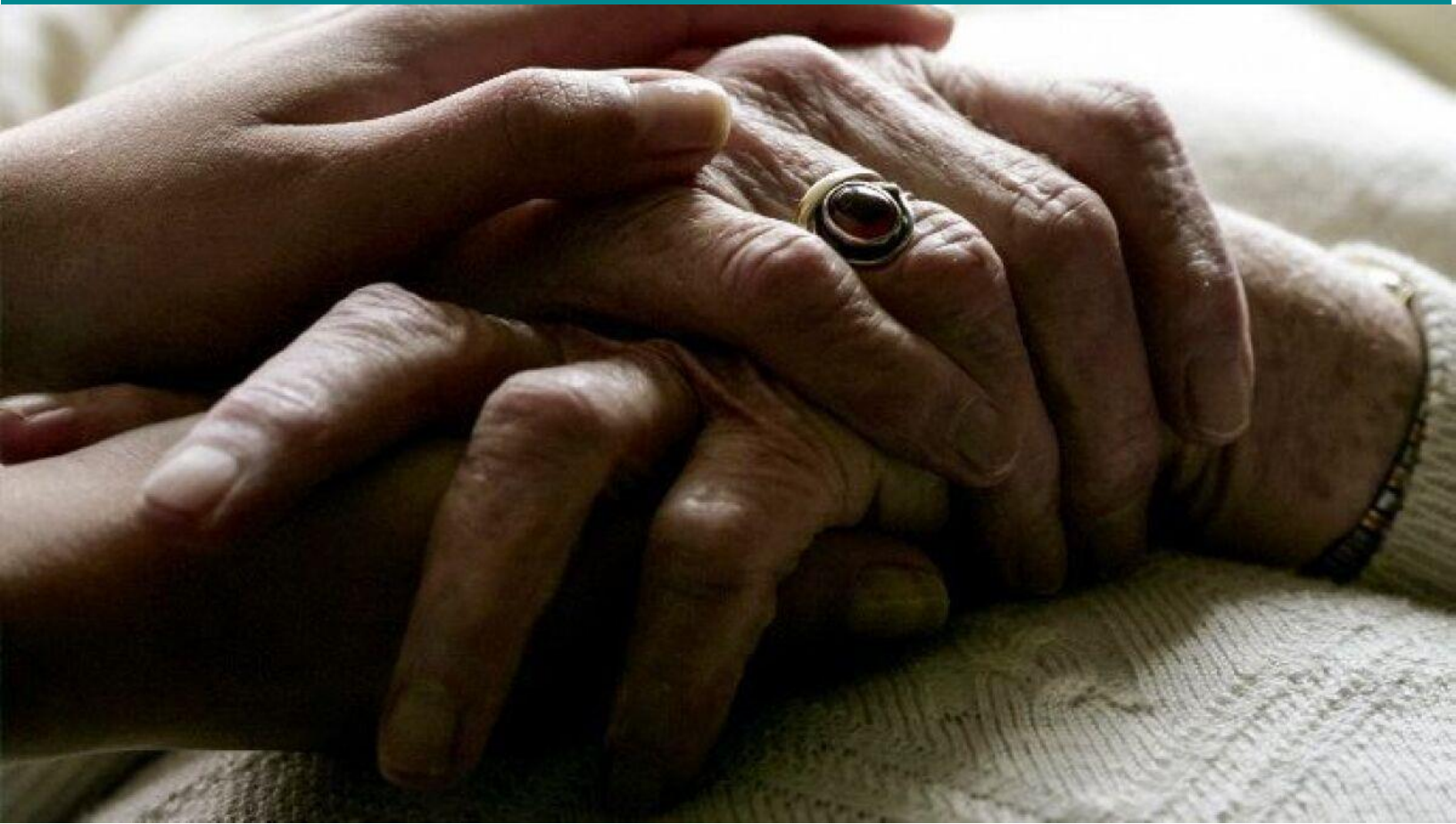
- Financial records up to date (Will, Benefit Designations).
- Any changes to the Advance Care Plan, MOST are documented.
- End of life recognition plans been reviewed, and any updates documented.
- Contact lists up to date.
- Will the person remain at home or hospice for their remaining days?
- Will palliative care services need to be arranged?
- Are employees aware of what to expect, what needs to be done, by who?
- Have housemates been debriefed and included in discussions?
- Is grief and loss support, training and counselling arranged?
- Is there a NO CPR form in place? Is the documentation in place and have staff been prepared and trained?

End of Life Recognition

Planning for how a person wants to be remembered is an important part of end-of-life care for the Supported Individual, their loved ones and those close to them. Documenting what type of service they would like, if they chose to have one and whether they would like a traditional ceremony or not, is all part of the process. Services can be pre-paid in advance, and in the event, help is needed they may be eligible for some government supports to cover the costs. The list below is an overview of some of the common planning steps for end-of-life recognition.

- Details for obituary
 - Vital statistics
 - Memberships and Associations
 - Hobbies
 - Family
 - Publishing
 - Local
 - Regional
 - Internet
- Pets – Who will care for any pets?
- Preferences (Burial/Cremation)
 - Cremation – What will be done with ashes?

- Cemetery Arrangements
 - Burial Plot
 - Vault
 - Mausoleum
 - Casket (Open/Closed)
 - Headstone
- Funeral Services
 - Before burial / cremation
 - After burial / cremation
 - Where:
 - Funeral Home
 - Church/Temple/Mosque
 - At the graveside
 - Other
- Special Ceremonies
 - Fraternal Orders, Military
- Traditional ceremony, memorial service or celebration of life
 - What activities (Celebration of life)
 - Spiritual, cultural activities
 - Pictures, photo album, videos
 - Music, special readings, passages
 - Music
 - Reception (i.e. Food, etc.)
 - Flowers (i.e. type, colours)
 - Casket Spray
 - Lid Arrangements
 - Standing spray
 - Matching baskets
 - Specialty Pieces
- Eulogies
 - Clergy
 - Friend
 - Combination
 - Video Eulogy
 - Other
- Memorial Cards (Funeral home, printed)
- Pall bearers (Usually 4 – 6 Needed) friends, relatives or funeral Home
- Charitable donations to be made in the person's name



AT THE TIME OF DEATH

Planned and Unexpected Deaths

Depending on the nature of the death there are different roles and responsibilities of health professionals and agencies. The BC Ministry of Health defines death in three categories:

1. A **natural expected death** – Where deterioration to death occurs in its natural sequence, but plans may not be in place.
2. A planned, **expected home death** – Where a person has chosen to die at home with the support of family and plans have been clearly made and documented beforehand.
3. An **unexpected or suspicious death** – Which **MUST** be reported to the Coroner.



Personal Support Network refers to those closest in knowledge, care and affection to the person. This can include family birth family / siblings, relations by marriage or contract and/or the family of choice (anyone they chose to have closest to them)

Planning for Death at Home

When home deaths are anticipated natural events, it is important to be aware of the following:

- ✗ The coroner does not need to be notified of an expected death from natural causes, unless there are concerns regarding the cause of death.
- ✗ Police do not need to be contacted when the death was expected.
- ✗ Ambulance / 911 should NOT be contacted when the death was expected.
- ✓ The family must contact a funeral home of their choice to make necessary advance arrangements. If the individual does not have family and/or network involvement, this can be arranged by the service providers.
- ✓ The funeral home must be aware of the anticipated death and the appropriate authorization(s) must be in place to contact them directly once death has occurred.
- ✓ Complete a *Notification of Expected Death at Home Form* as required.

Notification of Expected Death in the Home Form

A *Notification of Expected Death in the Home* form must be complete by the Attending Medical/Nurse Practitioner. The form is only valid for **three (3)** months after a physician has signed it. It must be renewed every three months until death occurs. Employees cannot sign this form if the Supported Individual does not have family or close, non-paid supports. It has been recommended that the funeral home on the form be contacted, prior to death, to confirm what happens once a death occurs and if the funeral home will accept a form that has not been signed.

Pronouncement of Death. Health care professionals may pronounce death (Physicians, Registered Nurses, Registered Psychiatric Nurses, and Licensed Practical Nurses). While there is no legal requirement that death be pronounced for expected/anticipated deaths, the family may choose to. A health care professional may need to be available to pronounce death.

At the Time of Death

Responding to the death of a person can be stressful regardless of the circumstances around the occurrence and how much preparation has happened to prepare for the loss. Leadership will play a primary role in responding and supporting the other team members when the death of a person being supported occurs.

The CLS has policies that will assist all employees in knowing what to do in the event of a death of a Supported Individual.

Please refer to the following policies for role specific responsibilities:

- Responding to the Death of a Supported Individual- Staffed Homes and Supported Living
- Responding to the Death of a Supported Individual – Home Share



FORMS

- Advance Care Plan Summary
- Advance Care Plan – Wallet Card
- Medical Order for Scope of Treatment (MOST)
- Early Detection Screen for Dementia (EDSD)
- No Cardiopulmonary Resuscitation (CPR) - Medical Order

Advance Care Plan Summary

Advanced Care Plan Summary

(Adapted from “My Voice – Advance Care Planning Guide”, Ministry of Health, 2020)

Full name (please print): _____ Signature: _____

Date Advance Care Plan was completed: _____ (dd/mm/yyyy)

Is this an update of a previous plan? Yes No

Advance Care Plan includes: (tick all that apply)

Beliefs, values and wishes (See ‘Forms’ for template)

Temporary Substitute Decision Maker (TSDM) list

When a TSDM is needed, one person is chosen from this list in the order below (the order is set by B.C. law) the person must be 19 years or older, be capable, have no disputes with the person, and have been in contact in the past year:

1. Spouse (married, common-law, same sex)
2. Son or daughter (age 19 or over, any birth order)
3. Parent (either, includes adoptive)
4. Brother or sister (any birth order)
5. Grandparent
6. Grandchild (any birth order)
7. Anyone else related to the person by birth or adoption
8. Close friend
9. A person immediately related by marriage

(optional) Standard representation agreement (Section 7)

- Form 1 – Certificate of Representative or Alternate Representative
- Form 2 – Certificate of Monitor
- Form 3 – Certificate of Person Signing for the Adult
- Form 4 – Certificate of Witnesses

(optional) Enhanced representation agreement (Section 9)

(optional) Advance Directive Form

(optional) Goals of Care

(optional) Medical Order for Scope of Treatment (MOST)

Greensleeve

Copies of this Advance Care Plan have been given to:

Name	Relationship	Phone
	Health Care Provider	

Comments / Notes

Prepared By Name _____

Signature _____

Date _____

Phone _____

Advance Care Plan – Wallet Card

*** This material was extracted from the “My Voice – Expressing My Wishes for Future Health Care Treatment Advance Care Planning Guide” produced by the British Columbia Ministry of Health.*

My full name is _____

In case of emergency, call:
_____ (name) _____ (phone)

My health care provider is _____

I have an advance care plan

with a representation agreement [sec 7 sec 9]

with an advance directive

I am an organ donor

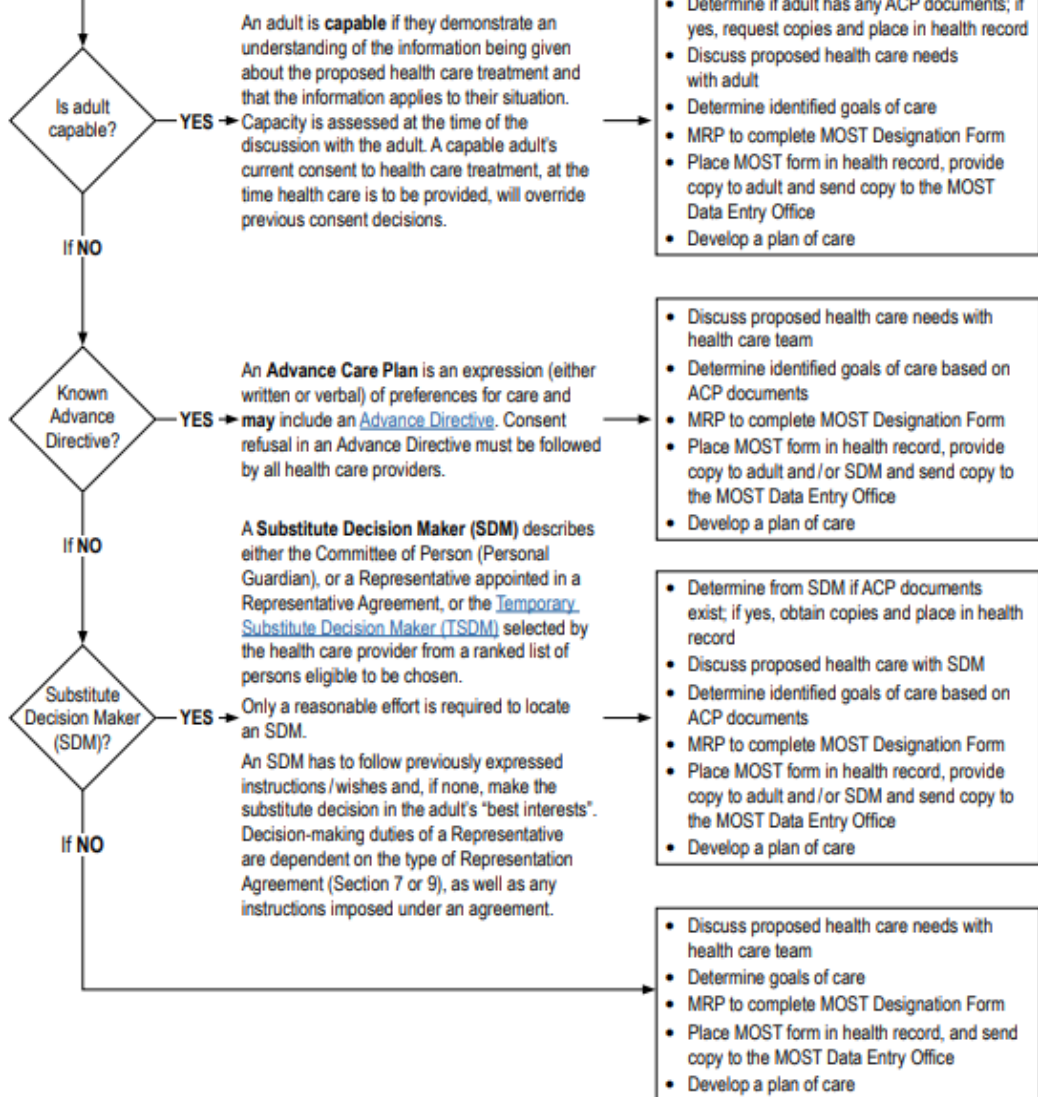
My important papers are located _____

Medical Order for Scope of Treatment

MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST)		Legal Name _____ <small>Last Name First Name</small>	
		Date of Birth _____ <small>MM/DD/YYYY</small>	
		Photo _____	
PART 1 – RESUSCITATION STATUS & MEDICAL TREATMENTS Most Responsible Practitioner (MRP) (Physician and/or Nurse Practitioner) to initial in the box beside the chosen resuscitation status/treatments (choose only ONE designation)			
M1	Supportive care, symptom management and comfort measures only: Allow a natural death. Care is for physical, psychological and spiritual preparation for an expected or imminent death. Do not transfer to higher level of care unless to address comfort measures that cannot be met in current location.		
M2	Medical treatments within current location of care including critical care interventions, cardiopulmonary resuscitation (CPR), intubation, and/or defibrillation. Current location: _____ Allow a natural death. Transfer to higher level of care only if adult's medical treatment needs cannot be met in current location. Goals of care and interventions are for cure or control of symptoms of illness that do not require critical care interventions, CPR, defibrillation and/or intubation.		
M3	Medical treatments including transfer to higher level of care but excluding critical care interventions, CPR, defibrillation and/or intubation: Allow a natural death. Medical treatments are for cure or control of symptoms of illness. Transfer to a higher level of care may occur if required for diagnostics and treatment.		
C0	Critical care intervention excluding CPR, defibrillation and intubation: Adult is expected to benefit from and is accepting of any medically appropriate investigations and interventions that are offered except CPR, defibrillation and intubation.		
C1	Critical care interventions including intubation, but excluding CPR and defibrillation: Adult is expected to benefit from and is accepting of any medically appropriate investigations and interventions that are offered except CPR and/or defibrillation.		
C2	Critical care interventions including CPR, defibrillation and/or intubation: Adult is expected to benefit from and is accepting of any medically appropriate investigations and interventions that are offered.		
PART 2 – SPECIFIC INTERVENTIONS (if applicable, refer to details in completed Patient Consent Record)			
Blood/Products <input type="checkbox"/> YES <input type="checkbox"/> NO		Nutritional Support <input type="checkbox"/> YES <input type="checkbox"/> NO	
Non-Invasive Ventilation <input type="checkbox"/> YES <input type="checkbox"/> NO		Dialysis <input type="checkbox"/> YES <input type="checkbox"/> NO	
Other _____			
PART 3 – SUPPORTING DOCUMENTATION (check all documents reviewed)			
<input type="checkbox"/> Previous MOST Form		<input type="checkbox"/> Plan of Care	
<input type="checkbox"/> No CPR Form (B.C.)		<input type="checkbox"/> Advance Directive	
<input type="checkbox"/> Representation Agreement		<input type="checkbox"/> Other	
<input type="checkbox"/> Section 9		<input type="checkbox"/> Section 7	
PART 4 – CONSULTATIONS Refer to consent process on reverse (check all individuals consulted)			
<input type="checkbox"/> Capable Adult		<input type="checkbox"/> Representative (name) _____	
<input type="checkbox"/> Personal Guardian (Committee) (name) _____		<input type="checkbox"/> Temporary Substitute Decision Maker (name) _____	
<input type="checkbox"/> Inter-professional health care team		<input type="checkbox"/> Adult incapable/SDM unavailable	
SUMMARY OF MRP ORDER (Physician and/or Nurse Practitioner)			
As the MRP I have considered the documents noted in Part 3 and discussed the benefits, consequences and preferences of the above Order with the individual(s) noted in Part 4.			
Name of MRP (please print) _____		College ID# _____	Signature _____
Date (dd/mm/yyyy) _____	Time (h:m) _____	MRP Office Phone # _____	Adult Location _____
Sent to MOST Data Entry Office _____		Date (dd/mm/yyyy) _____	Initials _____
REVALIDATION OF MRP ORDER			
<input type="checkbox"/> MOST FORM Revalidation (No Change)		Date (dd/mm/yyyy) _____	Name of MRP (print) _____
<input type="checkbox"/> MOST FORM Revalidation (No Change)		Date (dd/mm/yyyy) _____	MRP Signature _____
Sent to MOST Data Entry Office _____		Date (dd/mm/yyyy) _____	Initials _____

SUMMARY OF PROCESS TO DETERMINE MOST DESIGNATION

NEED FOR MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST) IDENTIFIED



KEY MESSAGE

Advance Care Planning (ACP) + MOST informs an adult's "Plan of Care". The priority sequence for obtaining consent is:

- 1) as communicated by a capable adult. A capable adult can change their decision about previous instructions; or
- 2) as written in an adult's Advance Directive, if known; and determine if other personal planning documents exist; or,
- 3) as communicated between an incapable adult's Substitute Decision Maker (if available) and health care team; or
- 4) as determined by an incapable adult's health care team

Early Detection Screen for Dementia



NTG-EDSD v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQJID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness

Visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

Early Detection Screen for Dementia

DATE COMPLETED _____

ORGANIZATION/AGENCY _____

NAME OF PERSON COMPLETING FORM _____

RELATIONSHIP TO PERSON (staff, relative, assessor, etc.) _____

DATES FORM PREVIOUSLY COMPLETED _____

NAME OF PERSON: FIRST NAME _____ LAST NAME _____

DATE OF BIRTH _____ AGE _____ SEX Female Male

BEST DESCRIPTION OF LEVEL OF INTELLECTUAL DISABILITY

- No discernable intellectual disability
- Borderline (IQ 70-75)
- Mild ID (IQ 55-69)
- Moderate ID (IQ 4—54)
- Sever ID (IQ 25-39)
- Profound ID (IQ 24 and below)
- Unknown

CURRENT LIVING ARRANGEMENT

- Lives alone
- Lives with spouse or friends
- Lives with parents or other family members
- Lives with paid caregiver
- Lives in community group home, apartment, supervised housing, etc.

GENERAL CHARACTERIZATION OF CURRENT PHYSICAL HEALTH

- Excellent
- Very Good
- Good
- Fair
- Poor

GENERAL CHARACTERIZATION OF CURRENT MENTAL HEALTH

- Excellent
- Very Good
- Good
- Fair
- Poor

DIAGNOSED CONDITION (check all that apply)

- Autism
- Cerebral Palsy
- Down Syndrome
- Fragile X Syndrome
- Intellectual Disability
- Prader-Willi Syndrome
- Other: _____

- Lives in senior housing
- Lives in congregate residential setting
- Lives in long term care facility
- Lives in other _____

COMPARED TO ONE YEAR AGO, CURRENT PHYSICAL HEALTH IS

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

COMPARED TO ONE YEAR AGO, CURRENT MENTAL HEALTH IS

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

CONDITIONS PRESENT (check all that apply)

- Vision Impairment
 - Blind (very limited or no vision)
 - Vision corrected by glasses
- Hearing Impairment
 - Deaf (very limited or no hearing)
 - Hearing corrected by hearing aids
- Mobility Impairment
 - Not Mobile – uses wheelchair
 - Not Mobile – is moved about in wheelchair

SEIZURES

- Recent onset seizures
- Long term occurrence of seizures
- Seizures in childhood, not occurring in adulthood
- No history of seizures

DIAGNOSTIC HISTORY

Mild Cognitive Impairment (MCI) or Dementia previously diagnosed?

- No
- Yes MCI Date of Dx _____
- Yes Dementia Date of Dx _____ Type of Dementia _____

Diagnosed By:

- Geriatrician
- Neurologist
- Physician
- Psychiatrist
- Psychologist
- Other _____

Reported date of onset of MCI/Dementia (when suspicion of dementia first arose) _____
Year/Month

COMMENTS/EXPLANATION ABOUT DEMENTIA SUSPICIONS

SIGNIFICANT RECENT (in past year) LIFE EVENT (check all that apply)

- Death of someone close
- Changes in living arrangements, work, or day program
- Changes in staff close to the person
- New roommate/housemates
- Illness or impairment due to accident
- Adverse reaction to medication or over-medication
- Interpersonal conflicts
- Victimization / abuse
- Other _____

(check columns as appropriate)

ACTIVITIES OF DAILY LIVING	Always been the case	Always but worse	New symptom in past year	Does not apply
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
LANGUAGE & COMMUNICATION	Always been the case	Always but worse	New symptom in past year	Does not apply
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
SLEEP-WAKE CHANGE PATTERNS	Always been the case	Always but worse	New symptom in past year	Does not apply
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
AMBULATION	Always been the case	Always but worse	New symptom in past year	Does not apply
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				
MEMORY	Always been the case	Always but worse	New symptom in past year	Does not apply
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				

Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
BEHAVIOR AND AFFECT	Always been the case	Always but worse	New symptom in past year	Does not apply
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
ADULT'S SELF-REPORTED PROBLEMS	Always been the case	Always but worse	New symptom in past year	Does not apply
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
NOTABLE SIGNIFICANT CHANGES OBSERVED BY OTHERS	Always been the case	Always but worse	New symptom in past year	Does not apply
In gait (e.g., stumbling, falling, unsteadiness)				
In personality e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

CHRONIC HEALTH CONDITIONS (check columns as appropriate)

*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)

	BONE, JOINT AND MUSCLE	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
1	Arthritis				
2	Osteoporosis				
	HEART AND CIRCULATION	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	HORMONAL	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	LUNGS/BREATHING	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	MENTAL HEALTH	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
13	Alcohol or substance abuse				
14	Anxiety disorder				
15	Attention deficit disorder				
16	Bipolar disorder				
17	Dementia/Alzheimer's disease				
18	Depression				
19	Eating disorder (anorexia, bulimia)				
20	Obsessive-compulsive disorder				
21	Schizophrenia				
22	Other:				
	PAIN / DISCOMFORT	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	SENSORY	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				

	OTHER	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
33	Cancer – type:				
34	Chronic fatigue				
35	Epilepsy / seizure disorder				
36	Heartburn / acid reflux				
37	Urinary incontinence				
38	Sleep apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

CURRENT MEDICATIONS

For reviews, attach list of current medications, dosage and when prescribed

- Treatment of chronic conditions,
Medication Name: _____
- Treatment of mental health disorders or behaviour problems
Medication Name: _____
- Treatment of Pain
Medication Name: _____

COMMENTS RELATED TO OTHER NOTABLE CHANGES OR CONCERNS

NEXT STEPS / RECOMMENDATIONS

- Refer to treating physician for assessment
- Review internally by clinical personnel
- Include in annual review/annual wellness visit
- Repeat in _____ months

Acknowledgement: Derived from the DSQIID (*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.

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www.aadmd.org/ntg/screening

National Task Group on Intellectual Disabilities and Dementia Practices

No Cardiopulmonary Resuscitation (CPR) - Medical Order

[Click to access form](#)



BRITISH COLUMBIA | Ministry of Health



BC Emergency Health Services
Provincial Health Services Authority

NO CARDIOPULMONARY RESUSCITATION – MEDICAL ORDER

Capable patients may request that no cardiopulmonary resuscitation be started on their behalf. This should be done after discussions with their doctor or nurse practitioner. "No cardiopulmonary resuscitation" is defined as no cardiopulmonary resuscitation (no CPR) in the event of a respiratory and/or cardiac arrest.

This form is provided to you or your substitute decision maker to acknowledge that you have had a conversation with a physician or nurse practitioner about a No CPR Order, and understand that no CPR will be provided in circumstances where you can no longer make decisions for yourself. It instructs people such as first responders, paramedics and health care providers not to start CPR on your behalf whether you are at home, in the community or in a residential care facility. The personal information collected on this form assists the health professionals noted above to carry out your wishes. If you have any questions about the collection of this information contact **HealthLink BC at 8-1-1** or go to www.gov.bc.ca/expectedhomedeadth.

You or someone at your location should have the form available to show to emergency help if they come to your aid. It is desirable that you wear a MedicAlert® no CPR bracelet or necklet to enable quick verification that you have a No CPR Order in place. To obtain a free No CPR bracelet/necklet, please:

1. Complete the form below
2. Fill out the MedicAlert Registration form which can be printed from: https://www.medicalert.ca/nocpr/resources/MedicAlert_Application_BC_NOCPR.pdf
3. Mail both of the forms to: MedicAlert Foundation Canada, Morneau Shepell Centre II, 895 Don Mills Road, Suite 600, Toronto ON, M3C 1W3

If you change your wishes about your no CPR preference, then please inform your doctor, nurse practitioner or residential care facility nurse, tear up the No CPR form, and contact MedicAlert if you enrolled with them for a No CPR bracelet or necklet.

PATIENT IDENTIFICATION	Patient Last Name	Birthdate (YYYY / MM / DD)
	Patient First and Middle Name(s)	Personal Health Number (PHN)
	Patient Address	Telephone Number
WITNESSED BY THE PATIENT, OR BY THE PATIENT'S SUBSTITUTE DECISION MAKER (SDM) WHEN THE PATIENT IS INCAPABLE	I, _____ (patient's name or patient's substitute decision maker if patient is incapable) have had a conversation with the undersigned physician/nurse practitioner about this No CPR Order in the event of cardiac or respiratory arrest. I understand that in the event of a cardiac or respiratory arrest, no cardiopulmonary resuscitation is to be undertaken.	
	Patient's Signature	Date Signed
	Signature of the Patient's Substitute Decision Maker	Date Signed
	Relationship of the Patient's Substitute Decision Maker to the Patient (e.g. representative, committee of person, or temporary substitute decision maker)	
SECTION TO BE COMPLETED BY PHYSICIAN/NURSE PRACTITIONER		
STATUS OF MEDICAL ORDER	The above identified patient has expressed wishes to not have CPR in the event of cardiac or respiratory arrest. I have discussed the patient's health status, life expectancy, and expressed wishes with the patient/patient's substitute decision maker. Based on this discussion, I order that in the event of a respiratory and/or cardiac arrest no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect until cancelled or repealed.	Date
	<input type="checkbox"/> Patient (or SDM) agrees and has signed this form <input type="checkbox"/> Patient (or SDM) agrees but has declined signing this form	
ATTENDING PHYSICIAN/NURSE PRACTITIONER		ALTERNATE PHYSICIAN/NURSE PRACTITIONER
Name of Attending Physician / Nurse Practitioner		Name (Print)
License Number of Physician / Nurse Practitioner	Phone Number	Phone Number
Address	Signature	

COPY 1 – TO PATIENT; **COPY 2** – TO ATTENDING PHYSICIAN/NURSE PRACTITIONER; **COPY 3** – IF APPLICABLE, TO HOME & COMMUNITY CARE OR RESIDENTIAL CARE FACILITY

HLTH 302 Rev. 2019/03/26

This form can be found at www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf

PATIENT/ FAMILY INSTRUCTIONS

Looking at this form may be one of the most difficult things you have ever done. Many thoughts and emotions may surface. So often people try to ignore their mortality, yet we all know it is one of the facts of life: we all, one day, will die.

This form is a medical order that reflects your wishes about what you would like to have happen in the event you stop breathing or your heart stops beating. Take time to thoughtfully consider your wishes and ask your health care professionals what resuscitation would entail and any risks to quality and/or quantity of life that could accompany resuscitation if you decided to have it.

Whether you live at home or in a residential care facility, your care team will help you and/or your substitute decision maker to make choices and plans for end-of-life-care. If you have a life-limiting illness and are choosing to die at home, you will need to make additional plans. The steps you will need to consider are listed below.

If you are a family member who is asked to consider this document on behalf of your loved one, all of what is said above applies also. This can be a stressful decision. Remember to seek support from trusted family members, friends and/or a spiritual advisor if you have one and your health care team.

IF YOU WANT TO DIE NATURALLY AT HOME, CONSIDER THESE STEPS

INDIVIDUAL / FAMILY

What to Do Ahead of Time

- > Discuss the option of an in-home death with your physician/nurse practitioner and community nurse.
- > Make a written plan with your physician/nurse practitioner and community nurse so you are clear about what will happen and so family, friends and others may support your decisions and respect your wishes and know what to do at the time of death. You need to write in your plan:
 - who will pronounce death, IF pronouncement is planned. Pronouncement is NOT necessary if a "Notification of Expected Home Death" form has been completed earlier by you and your doctor or nurse practitioner. The form can be found at www.gov.bc.ca/expectedhomedeath.
 - how your physician/nurse practitioner can be reached;
 - what alternate arrangements have been made should your physician/nurse practitioner be unavailable or cannot be reached;
 - which funeral home will be called to transport the deceased.
- > Make prearrangements with a funeral home. Such arrangements will normally involve selecting the funeral home and making plans with the funeral director for transportation of the deceased after death and the method of final disposition. For information on funeral homes in your area, you could contact the B.C. Funeral Association at 1-800-665-3899.
- > Ensure that a copy of this form is easily available in your home. If you are away from your home for any reason, take the form with you so it's available should it be necessary.

FAMILY / FRIENDS

What to Do at the Time of Death

- > DO NOT CALL 911, the ambulance, coroner, police, or fire department. Review your written plan for who to contact at the time of death.
- > CALL family, friends, and the spiritual advisor, if any, you would like to have present.
- > CALL the physician/nurse practitioner or community nurse to pronounce death IF a "Notification of Planned Home Death" form has NOT been completed, AND/OR pronouncement is planned.
 - If your physician/nurse practitioner or community nurse cannot be reached, CALL the backup physician/nurse practitioner or community nurse if prearranged.
- > IF a "Notification of Planned Home Death" form HAS been completed AND is in your home, call the funeral home after one hour or more has passed since your loved one's breathing has stopped.
 - You do NOT need to call a physician/nurse practitioner about completing a Medical Certificate of Death form. The funeral home can contact the physician or nurse practitioner to obtain a signed certificate within 48 hours, because the body cannot be released for burial or cremation without it.

People to Call	Name	Telephone Number
Phys/Nur. Practitioner		
Alternate Practitioner		
Community Nurse		
Funeral Home		
Spiritual Advisor		
Home Support Agency		
Hospice Program		
Family and Friends		

For more information, go to www.gov.bc.ca/expectedhomedeath

There are communities in British Columbia without physicians or nurse practitioners who live in the community and without a funeral home. It is essential that these situations be discussed by the patient and family and physician/nurse practitioner and an appropriate plan suitable for the community be made in advance.

PRINT

CLEAR FORM



GLOSSARY and RESOURCES

Glossary

Term	Definition
Acute Care	Acute Care (hospital) is where a person receives active but short-term treatment for a severe illness, injury, urgent medical condition, or during recovery from surgery.
Advance Care Plan	A written summary of a person's wishes about the kind of care they want or do not want in the event they are not able to communicate for themselves.
Advance Directive	A written statement of a person's wishes regarding medical treatment made to ensure the wishes are carried out should the person not be able to communicate them.
Beneficiary Designations	Naming someone to receive money, property, investments, or any other specific benefit.
Break Through Pain	A sudden increase in pain that happens when a person has chronic pain from a terminal illness.
Comfort Measures	Treatments to keep a person comfortable. (e.g. pain relievers, psychological support, physical care, oxygen, etc.,)
CPR	Cardiopulmonary Resuscitation is a medical procedure used to restart a patient's heart and breathing when the heart and/or lungs stop working unexpectedly.
Critical Care	Critical Care Services (hospital) meet the needs of people facing an immediate life-threatening health condition
Critical Illness	is a serious medical condition where the person may recover from.
End of Life Care	Refers to health care provided at the end of a person's life. This type of care focuses on people living the way they choose during their last weeks and on comfort care until the time of death.
Enduring Power of Attorney	A legal document that allows a person to appoint someone they trust to make decisions if they no longer have the capacity to do so.
Enhanced Representation	A legal document that allows a person to choose who will make health care and personal care decisions for them.
Goals of Care	The process of documenting a person's values, wishes, and goals for medical treatment as part of advance care planning.
Greensleeve	A plastic pocket that holds important Advance Care Planning documents.
Intubation	Tracheal intubation is the placement of a flexible plastic tube into the windpipe to maintain an open airway and to be able to administer certain drugs.
Last Will & Testament	A legal document that communicates a person's final wishes for their assets and dependents and end of life recognition.
Medical Order - Scope of Treatment	A doctor's order based on advance care planning conversations that explore a person's values, goals, and the range of treatments available.
Palliative Care	Care provided for people who have life-limiting illness that focuses on providing good quality of life. It can include medicines, physical care, socio-emotional services, cultural and spiritual support for the person and those caring for them.
Representation Agreement	An agreement where a person is named by an adult to support the adult to make decisions or make decisions on their behalf. There are two types of Representative Agreements: Section 7 and Section 9.
Temporary Substitute Decision Maker	A person who makes medical decisions and provides consent for treatment or withdrawal of treatment for another person when they are no longer able to communicate their wishes on their own.
Terminal Illness	Is an illness or condition that cannot be cured or adequately treated and will likely result in a person's death within the next 12 months.

Resources

This resources list is intended to provide a selection of pre-existing resources developed by other associations and government entities in Canada and in other countries that we think would be helpful for BC Service Providers to explore, use, and/or adapt to their needs. The developers of these resources have put considerable time and thought into customizing them to meet their needs. While we do not assume any role in endorsing their approaches, we do feel having this array of materials can be a good starting place for organizations to develop their own internal resources that fit their philosophy and approach using selected resources as their templates.

Understanding that each organization has their own internal philosophy and approach, and many have started to develop their own resources, we have chosen to develop this bibliography rather than pulling all the ideas presented in these documents into ‘one size fits all’ templates for BC service providers.

Relevant Sections

- A. Plain Language Resources
- B. Resources for Members of Person’s Support Team
- C. CLBC Resources
- D. Advance Care Planning from a Cultural Perspective
- E. Websites of Interest

A. Plain Language Resources

Resources About Death, Grief, and Loss

This booklet was produced by Down Syndrome Scotland and provides helpful information augmented by lots of visuals. They can be used as is to have discussions with individuals you support. Alternatively, a version that is local to your BC community could be created.

- **Let’s Talk About Death: A Booklet About Death and Funerals for People with Down Syndrome**
https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DSS_LETS-TALK-ABOUT-DEATH_WEB.pdf

Resources to Think About Aging and Age-Related Health Issues

These plain language resources, also from Down Syndrome Scotland, provide helpful information about what could happen as people age. They use references that reflect the cultural context and could be easily adapted to integrate terms that are familiar to the individuals you serve. These resources can also be personalized and incorporated into a late life planning conversation. Although focused on people with Down Syndrome, the information is relevant to any adult with a developmental disability who is aging.

- **Let’s Talk About Aging: A Booklet About Getting Older for Adults with Down Syndrome**
https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DOWNS-SYNDROME-SCOTLAND_LETS-TALK-ABOUT-GETTING-OLDER_AW_WEB.pdf
- **Let’s Talk About Dementia: A Booklet for Adults with Down Syndrome**
<https://www.dsscotland.org.uk/wp-content/uploads/2020/01/LETS-TALK-ABOUT-DEMENTIA.pdf>
- **Let’s Talk About the Menopause: A Booklet About Menopause for Adults with Down Syndrome**
https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DSS_LETS-TALK-ABOUT-THE-MENOPAUSE_AW_WEB.pdf

Resources for Those Supporting Individuals with Age Related Health Issues

A resource created by Down Syndrome Scotland provides helpful information about dementia for the supporters in a person's life, including family and paid employees. This book is constructed to read and talk about together.

- **Living with Dementia: A Book about Dementia for families and carers of a person with Down Syndrome**
https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DSS_LIVING-WITH-DEMENTIA_AW_WEB.pdf

This resource was developed by the National Down Syndrome Society in the US

- **Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers**
https://www.ndss.org/wp-content/uploads/2017/11/NDSS_Guidebook_FINAL.pdf

These booklets were developed by the Down Syndrome Association in the UK and provides information on bereavement and supporting individuals.

- **Bereavement**
<https://www.downs-syndrome.org.uk/wp-content/uploads/2020/06/Bereavement-21-8-DSMIG.pdf>
- **Getting Older**
<https://www.downs-syndrome.org.uk/wp-content/uploads/2020/06/Ageing-Final-Format-5th-April-DSMIG.pdf>

Planning For End of Life and After Death

These two resources provide helpful templates and plain language information for individuals about supported decision making. They can be adapted to your organization. Supported decision making may be part of late life planning as individuals participate in conversation, consider their wishes, and make choices about how they wish to be supported and by whom.

- **Plain Language Introduction to Supported Decision Making from Inclusion Saskatchewan**
https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_9c518858a895465693153961d87a1dda.pdf
- **Supporting Me to Make a Decision: A Quick Guide**
This plain language reference provides a helpful guide for individuals as they exercise their self-determination in planning processes. The reference is from Down Syndrome Society in the UK.
<https://www.downs-syndrome.org.uk/wp-content/uploads/2021/02/Quick-Guide-Supporting-me-to-make-a-decision.pdf>

A selection of additional plain language resources that offer examples of ways to support individuals as they consider and declare their personal choices re: end of life care and planning for after they die. All can be adapted to your particular organization and sections can form part of the late life planning process.

- **Thinking Ahead Matters: My Way, My Choice, My Life At the End**
https://coalitionccc.org/common/Uploaded%20files/PDFs/Thinking-Ahead-Booklet_web.pdf
- **Living Well: Thinking and Planning for the End of Your Life**
<https://creativeoptionsregina.ca/wp-content/uploads/2015/03/Thinkind-and-Planning-for-the-End-of-Your-Life.pdf>

- **What If - Celebrating My Life**
<http://www.grpcc.com.au/wp-content/uploads/2016/08/What-If-Celebrating-My-Life-Plan-EOL-2013.pdf>
- **Infographic about Advance Care Planning – People’s Law School**
https://assets.ctfassets.net/wzm83lc7g93q/3jg2swqidgXQ7NZy5CIMFX/9cc996f3b734b4b4a29a5928791df034/advance_care_planning_infographic.pdf
- **My Life, My Wishes – Sharing My Journey**
https://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/publication/MyLifeMyWishes_EOLPlanning_6-15Fillable.pdf
- **Accessible Planning Tool: Glancing Back, Planning Forward**
<http://www.professionalpalliativehub.com/sites/default/files/Accessible%20Planning%20Tool.pdf>
- **Preparing for Death – Victoria Hospice**
https://victoriahospice.org/wp-content/uploads/2019/07/preparing_for_death.pdf

B. Resources for Members of Person’s Support Team

(Including family, friends, advocates, and paid employees)

These resources provide examples of ways to support individuals and also remind us of the importance of starting these conversations, honouring grief and loss, and supporting individuals to participate in planning and thinking about how they want to live all the days of their lives.

Talking about Aging and End of Life

- **Living Well: Using Person-Centred Planning Tools with People Who Have A Life Limiting Illness**
<http://www.helensandersonassociates.co.uk/wp-content/uploads/2015/02/livingwell-hull.pdf>
- **Your Conversation Starter Kit: When It Comes to End of Life Care, Talking Matters**
<https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf>
- **Towards Excellence in Hospice Care: Widening Access to Palliative Care for People with Learning Disabilities**
https://www.eolc.co.uk/uploads/Widening_access_to_palliative_care_for_people_with_learning_disabilities.pdf
- **Talking End of Life with People with Intellectual Disabilities**
<https://www.caresearch.com.au/tel/tabid/4881/Default.aspx>
- **The Middle Years and Beyond: Transitions and Families of Adults with Down Syndrome**
https://oadd.org/wp-content/uploads/2012/01/41012_JoDD_18-2_59-69_Jokinen_et_al.pdf

Working Effectively with Health Care Professionals

- **Improving Emergency Care for Adults with Developmental Disabilities: A Toolkit for Providers**
Implementing Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers
<https://www.porticonetwork.ca/web/hcardd/healthcareresources/clinicians-and-service-providers>
- **Health Link BC – Advanced Care Planning Resources**
<https://www.healthlinkbc.ca/more/health-features/planning-advanced-care>

Coping with Grief and Loss

- **Supporting People with Disabilities Coping with Grief and Loss**
http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/mental-health/feelings/SUPPORTING_PEOPLE_WITH_DISABILITIES_COPING_WITH_GRIEF_AND_LOSS.pdf

Advance Care Planning and Representation Agreements

- **Infographic about Representation Agreements - The People's Law School**
https://assets.ctfassets.net/wzm83lc7g93q/2QGRhWGolmiJy9uxmDyqJx/b405c182d7de82f0984941590db89636/understand_representation_agreements_infographic__1_.pdf

Easy Read Advance Care Planning (ACP) Guide – Fraser Health

This fillable ACP picture-based workbook can help an individual, and the people who matter to them, work through the steps of planning for their future health.

Unique features include:

- Created for anyone who may process information differently, for example
 - People living with brain conditions such as Dementia, Huntington's disease, ALS, Parkinson's disease, or tumors; or impairments from health events such as aphasia from Stroke or other limitations from Brain Injury.
 - People living with disabilities.
 - People with limited English literacy (when translation is not available).
- Includes guidance for caregivers and support people to support other through the process.
<https://patienteduc.fraserhealth.ca/file/my-voice-action-a-workbook-for-advance-care-pla-583174.pdf>

Please Note: this *Easy-Read* version is based on a previous resource: [My Voice in Action](https://patienteduc.fraserhealth.ca/file/my-advance-care-plan-a-companion-workbook-to-my-vo-428644.pdf) (<https://patienteduc.fraserhealth.ca/file/my-advance-care-plan-a-companion-workbook-to-my-vo-428644.pdf>)

C. CLBC Resources

CLBC has created a policy which all service providers are expected to follow. Their policy can be found on their website.

End of Life Policy

- https://www.communitylivingbc.ca/wp-content/uploads/END_OF_LIFE_POL_10_19_2016-1.pdf
- https://www2.gov.bc.ca/assets/gov/health-safety/home-community-care/care-options-and-cost/expectedplanned-home-deaths/expected_home_death.pdf

Resources on Aging Created by CLBC

CLBC has developed a number of resources to support individuals as they age, as well as support their families and caregivers. These resources can be found under provincial projects on their website and hard copies are available in local CLBC offices.

- [Aware Share Care Website](#)
 - The website www.AwareShareCare.ca provides helpful tips and resources to assist in better planning for aging.
- [Looking Forward to the Future – Storybook](#)
 - “*Looking Forward to the Future*” is a book of stories about how people have created positive outcomes for individuals with developmental disabilities as they age.

- [Aging with a Developmental Disability – Guide](#)
 - “Aging with a Developmental Disability” is a planning guide for families and others that support adults with developmental disabilities who are getting older.
- [Aging Parents / Caregivers Pamphlet](#)
 - The Aging Parents / Caregivers Pamphlet informs aging parents and caregivers of the need to, and benefits of, making a plan with their family member.

D. Advance Care Planning from a Cultural Perspective

The First Nations Health Authority has developed this resource as a conversation guide a tool to learn about Advance Care Planning. The goal of planning is to support individuals, families, and health care providers, to walk side-by-side through a person’s illness and journey into the Spirit World.

- **Your Care, Your Choice – Planning in Advance for Medical Care**
<https://www.fnha.ca/WellnessSite/WellnessDocuments/FNHA-Your-Care-Your-Choices-Planning-in-Advance-for-Medical-Care.pdf>

This document focuses on care conversations for Two-Spirit and Lesbian, Gay, Bisexual, Trans, Queer, and all sexual and gender-diverse people.

- **Planning for My Care for people who identify as Two Spirit or LGBTQ+**
<https://www.virtualhospice.ca/2SLGBTQ/media/igkp01nf/2slgbtq-planning-for-my-care.pdf>

E. Websites of Interest

There are a variety of websites that provide resources for a diverse population which can be used for training, reference, and support. A selected few include:

Canadian Virtual Hospice - A comprehensive resource with resources in a variety of areas including information on death and dying, planning for end of life, grief, culture and a new suite of materials to support the LGBTQ2+ community.

<https://www.virtualhospice.ca/>

NIDUS - Nidus Personal Planning Resource Centre and Registry *is a non-profit charitable organization. Nidus has helped thousands of people make and register Representation Agreements and learn about other legal planning documents.*

www.nidus.ca

PLAN: Planned Lifetime Advocacy Network - Founded in 1989, PLAN works collaboratively to build personal support networks, make plans to secure the future, and bring families together for mutual support, learning and community leadership.

<https://plan.ca/>

L’Arche Canada: Aging and Disability – Preparing for End of Life - This website provides examples of ways the organization has supported those they support to prepare for their end of life including examples of memorial services, celebration booklets, links to other resources, and testimonials from individuals and their network members.

http://www.aging-and-disability.org/en/ending_life_well

NTG: The National Task Group on Intellectual Disabilities and Dementia Practices - This organization advocates for research and resources for people with intellectual disabilities and their families affected by Alzheimer’s Disease or dementias. The Early Detection Screen, found under the Resources tab, is used to document changes in an individual’s functioning which may be indicators for dementia.

<https://www.the-ntg.org/ntg-edsd> The Early Detection Screen is being used by organizations in BC to assist with monitoring changes for people they serve. <https://www.the-ntg.org/>

The Down Syndrome Research Foundation - This website features a Resource section which has educational videos, links to others resources, and information for families and caregivers.
<https://www.dsrf.org/>

The Alzheimer's Society - Comprehensive website offering information on links to resources, including groups and workshops in BC. Many resources have been translated into other languages.
<https://alzheimer.ca/bc/en>

Birmingham Research Park - Organization based in the UK which has produced resources on aging and people with intellectual disabilities.
<https://www.bild.org.uk/>

ConnectABILITY - ConnectABILITY, is a website and virtual community dedicated to lifelong learning and support for people who have an intellectual disability, their families, and support networks. The site places an emphasis on accessible, self-directed access to valuable information and tools. A section on resources for seniors has extensive information available.
<https://connectability.ca/en/>

Indigenous Cognition and Aging Awareness Research Exchange - This research initiative provides information and resources to support Indigenous communities respond to aging related changes. New Canadian Assessment tools are now included on the website.
<https://www.i-caare.ca/>



community **living** society

7th Floor – 713 Columbia Street

New Westminster, BC

V3M 1B2

604.523.0303

www.communitylivingsociety.ca

*Every story has an end,
but in life
every ending is a new beginning.*

- Unknown